

# Newborn Screening Update

## Michigan Newborn Screening Program

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## Introducing .....

Tammy Ashley began her position as the NBS Coordinator in October, 2005, just as the NBS Program was moving from one location to another. This did not deter her enthusiasm as she “hit the ground running.” Her role is to serve as a liaison to the three medical management centers, the laboratory, and treatment centers. Tammy will be working closely with families whose child has been diagnosed with one of the NBS identified disorders to ensure that the child has a medical home.

Tammy received her Bachelor and Master degrees in Nursing from Michigan State University. She is a certified Family Nurse Practitioner and lactation consultant. Tammy has been a nurse in various hospitals in the area. She was also a family practice office nurse. She has worked in research, taught at the college level, and was a home care nurse. Most recently, Tammy was a Nurse Practitioner in a Women’s and Obstetric office center.

Tammy has taught CPR for 21 years. She has been a lactation consultant for 11 years and has taught childbirth education classes for 10 years.

In her free time, she enjoys the benefits of practicing and teaching yoga, gardening, cooking healthy meals and border collie herding classes.

Feel free to contact her with questions or concerns regarding the NBS program. Her phone number is 517-335-8959 her e-mail address is ashleyt1@michigan.gov

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## Why is it important to have the correct physician name on the NBS card?

First, let us consider the following scenario— an infant is found to have a strong positive result from an initial newborn screen. The physician noted on the NBS card is contacted to either repeat the screen or refer the infant to one of the medical management centers. The physician states that they are not the infants physician, and that they do not know which physician is. A call to the hospital produces the same result. When asked why the physician’s name was placed on the newborn screening card, the answers include:

- 1—“We always put the physician who is on call at the time the baby was born”
- 2—“The mother “never” knows who she will be taking the infant to for their initial checkup”
- 3—“You don’t know the “population” we are dealing with”

Which of these answers do you think will help locate the infant and assure that the proper care is provided? At your hospital, do you make the effort to speak with the mother regarding her choice of a health care provider for her infant? Do you know if this information is stressed during your childbirth education classes or pre-admission hospital visit? Do you know if your delivering physicians discuss this with their patients during the prenatal period?

Is the time it takes to ensure that the correct physician/clinic name is on the newborn screening card worth the effect it may have on the outcome of that infant who has a positive screen result? What if it was your child or grandchild, sister or brother, niece or nephew? The time has come to recognize the problem and work together to achieve a positive solution.

For those hospitals who have found a way to ensure that the information documented on the NBS card is accurate, we are aware of your efforts and appreciate them. Thank you!

## Contacts

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## A Few Reminders ...

### Perinatal Hepatitis B Prevention Program (PHBPP) Reminder:

The Perinatal Hepatitis B Prevention Program (PHBPP) works to prevent transmission of the hepatitis B virus. The program works to accomplish this goal by:

- Identifying hepatitis B surface antigen-positive (HBsAg +) women.
- Ensuring infants born to HBsAg + women receive hepatitis B immune globulin (HBIG) and hepatitis B vaccine within 12 hours of birth, two additional doses of hepatitis B vaccine and post-vaccination serology.
- Identifying, testing and treating their household and sexual contacts.
- Providing education and case management for everyone enrolled in this program.

Despite these efforts, many HBsAg + women deliver without being reported. Infants born to HBsAg + women who do not receive the appropriate prophylaxis are at high-risk of developing chronic hepatitis B or liver disease later in life.

For many years, the newborn screening (NBS) cards have been a valuable tool in identifying HBsAg + women that have not previously been reported to the PHBPP. While this method has been effective in identifying additional cases, there were still 20,000 NBS cards missing the mother's HBsAg status in 2005.

In an effort to help us prevent the transmission of hepatitis B, please:

- Do NOT hold the NBS cards. The babies need to be screened within 24-36 hours of birth and the NBS cards need to be mailed to the Michigan Department of Community Health (MDCH) shortly thereafter.
- Complete the mother's section in the middle, right-hand side of the NBS card, and please make sure that every card is marked with the mother's HBsAg status, test date, and the results of her test.
- Test the mother **STAT**, if the HBsAg status is unknown.
- Confirm the mother's HBsAg status, even if the card must be sent to the MDCH prior to obtaining the mother's HBsAg status.
- Report all HBsAg + results to the PHBPP.

If your staff is unable to obtain the mother's HBsAg status, please contact our office so that we can follow-up to confirm her status.

If you have any questions about this process, please contact Pat Fineis at 517-335-9443, or toll free at 800-964-4487, or by e-mail at [fineisp@michigan.gov](mailto:fineisp@michigan.gov). In southeast Michigan, please contact Kari Tapley at 313-456-4431, or by e-mail at [tapleyk@michigan.gov](mailto:tapleyk@michigan.gov)

### NBS Follow-up Changes:

Physician offices, clinics, and other health care providers are requested to contact the birthing hospital for newborn screening results prior to contacting the state. Keep in mind that the state **will contact** the physician/clinic noted on the NBS card **when** the NBS result is **positive or presumptive positive**.

### NBS Cards:

Remember, if a mistake is made while completing the pink repeat screening card or the pink repeat screening card is outdated simply discard it. Please **do not** send the pink repeat screening cards to the state requesting credit. When sending the blue initial screening card for credit, remember to remove any blood that is on the card and include the form explaining the reason for the credit request. This form can be found on the NBS webpage [www.michigan.gov/newbornscreening](http://www.michigan.gov/newbornscreening). If you require a supply of either the pink or blue NBS cards, contact Val Klasko at 517-241-5583 or [KLASKO@michigan.gov](mailto:KLASKO@michigan.gov). Thanks!

### Ink, Tape, and Stickers:

Please remember to use only black or blue ink when completing the NBS cards. Various other ink colors do not photocopy or scan well resulting in a delay in the NBS process.

Please remember **do not** apply tape or stickers to the NBS card. This causes a delay during the process when the various parts of the cards are separated in the state lab. The end result is a delay running the screening tests and reporting screening results. Thanks!

# A Mother's Story

My name is Theresa and I am a Save Babies Through Screening Foundation volunteer (<http://savebabies.org>). My story is a bit different than those of newborns who are either diagnosed too late or misdiagnosed. My story is that of a young girl that lived to be 20 years old, and who died mysteriously and suddenly after a camping trip with friends.

My daughter Michelle, had been sick, really sick, only once in her life. That was when she was two years old. The doctors tested her for over 70 different diseases and possible illnesses, all tests which came back negative. After a week in intensive care, in a comatose state, she suddenly improved. The doctors stated that “what ever she may have had” must have been “cured” and that there wasn’t enough of whatever virus it “could have been” left to detect in the tests they were running. Her illness at that time was deemed “a fluke”. For the next 18 years she lived a very normal and very uneventful medical life.

At 20 years old she went camping with friends. She climbed a mountain and came back to the campsite tired and not really willing to eat much, so she slept instead. A few hours later she became very ill and by morning she still hadn’t eaten. Her friends felt she had contracted “the flu”. Her condition worsened to the point to where they took her to the Emergency room.

After many tests and several hours of waiting they determined that she “needed to sleep it off” convinced it was some type of drug use or alcohol. Though neither had been detected in her system. She was moved from the Emergency room to “Observation” where she died within a few hours.

After 4 months the Medical Examiner ruled her death “died of natural causes, cause unknown”. As her parent I was told “these things happen” and “sometimes people just die and we don’t know why”. I can not express the anger and hostility that took over my life and the frustration our family felt as we were treated as if we were “parents in denial” or that some how Michelle had contributed to her own death.

Our answers came 14 months after she died from the doctor who treated her in the Emergency room. He also didn’t understand how a perfectly healthy girl, could die so quickly at 20. With our permission, he had continued to have tests run from “samples” that had been kept at the Medical Examiners office.

Michelle had died of Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD), a rare hereditary disease that is caused by the lack of an enzyme required to convert fat to energy. People with MCADD cannot fast for very long. Remember she hadn’t eaten after climbing the mountain with her friends.

Thank you for you time.

Theresa (Mother to Michelle born 5/21/1977 & died on 3/16/1998) *Note: Michigan began screening for MCADD in 2003.*

## Information Sharing ...

Hospitals and other providers are invited to share information on their practices, policies, procedures, and experiences in an effort to improve the NBS process. This information is not to be considered a “requirement” of the NBS program. It is merely a “sharing of ideas” that you may choose to evaluate for use in your facility. If you would like to contribute an idea to share, please e-mail the information with a contact name, phone number, and permission to include the information in the NBS Update to [mccaustlandm@michigan.gov](mailto:mccaustlandm@michigan.gov).

## Information to share ...

### January is National Birth Defects Prevention Month!

**Why Birth Defects Prevention Month?** January is designated National Birth Defects Prevention Month to highlight the impact of birth defects on public health. Each year birth defects affect one in every 33 births in the United States. About 10,000 Michigan babies are born with some type of congenital anomaly every year. Birth defects remain the leading cause of infant death and contribute to an increased risk of mortality beyond a child's first year of life. Data from the Michigan Birth Defects Registry (MBDR) demonstrate an infant death rate for children born in 2002 with a reportable condition to be **40.9 deaths** per 1,000 MBDR cases. This compares to an infant death rate of **7.6 deaths** per 1,000 for all resident infants born in Michigan during the same year. In addition, factors such as specialized medical care, support services, special education, lost wages, and lost productivity merely scratch the surface of the emotional and financial implications of birth defects and disabilities. Birth defects not only impact affected individuals and their families, but ultimately, public health.

**What causes birth defects?** Both genetic and environmental factors contribute to the etiology of birth defects. Although the causes of most birth defects remain unknown, achieving optimal preconceptional maternal health is one strategy that can help reduce the risk of birth defects. Some birth defects are preventable. The importance of preconceptional health in lowering the impact of birth defects is the focus of national Birth Defects Prevention Month 2006.

**Why focus on preconceptional health?** The importance of achieving optimal health for women of childbearing age *prior* to conception, and the role preconceptional health plays in the prevention of birth defects, cannot be overemphasized. Since approximately 50 percent of pregnancies are unplanned, there is an *urgent* need for health care providers to incorporate prevention messages that foster healthy preconceptional behaviors into *every* aspect of health care for women in their reproductive years.

**What should women do?** Achieving good preconceptional health includes:

- \*\* Consume 400 micrograms of folic acid daily
- \*\* Knowing one's family history
- \*\* Having a check-up from a health care provider prior to conception
- \*\* Ensuring that immunizations are up-to-date
- \*\* Seeking reproductive genetic counseling, if appropriate
- \*\* Managing chronic maternal illnesses such as diabetes, hypertension, seizure disorders, lupus or phenylketonuria (PKU)
- \*\* Avoiding exposure to alcohol, nicotine and recreational drugs
- \*\* Ensuring that prescription medication and herbal supplements are safe at the time of conception and during early pregnancy, and avoiding harmful occupational and environmental exposures
- \*\* Avoiding harmful occupational and environmental exposures

In addition, avoiding infections and ensuring protection against domestic violence are other important elements of preconceptional health.

## Information to share continued...

Of all the strategies mentioned above, perhaps the most important for every woman of childbearing age is taking a daily multivitamin that contains 400 micrograms (400 mcg or 0.4 mg) of folic acid in addition to consuming a healthy, varied diet. Up to 70% of neural tube defects such as spina bifida and anencephaly can be prevented by daily folic acid intake of 400 micrograms prior to conception and throughout the first trimester of pregnancy. Research on folic acid continues to expand our knowledge about the benefits of this important cofactor. Folic acid consumption may reduce the risk of other birth defects including cleft lip/palate, congenital heart defects, limb-reduction defects, urinary tract defects and Down syndrome. Furthermore, folic acid intake is beneficial for both women and men throughout the lifespan. It may reduce the risk of cardiovascular disease/stroke; cervical, colon and lung cancer; and Alzheimer's disease.

The **only** birth defect that is 100% preventable is fetal alcohol spectrum disorder (FASD). FASD is a set of physical, behavioral and cognitive birth defects that can result when alcohol is consumed during pregnancy. FASD is one of the leading known preventable causes of mental retardation. It is an irreversible, lifelong condition that affects every aspect of a child's life and the lives of affected families. It is estimated that 1 in 1,000 children born each year in the United States has fetal alcohol syndrome (FAS), the most severe outcome after prenatal exposure to alcohol. Researchers estimate that up to 10 times as many children are born each year with other prenatal alcohol-related conditions. Women should not consume alcohol when they are pregnant or planning a pregnancy—there is no known safe amount.

**Can these strategies make a difference?** The good news is that prevention efforts *do* offer hope for reducing the number of families affected by birth defects. The essential public health message for Birth Defects Prevention Month 2006 is that achieving preconceptional health matters—both for women of childbearing age and their future offspring.

The Michigan Department of Community Health (MDCH) Birth Defects Program is grateful to have received cooperative agreement funding from the Centers for Disease Control and Prevention (CDC) since 1999 to support birth defects surveillance, prevention and intervention efforts. Current CDC funding will supplement program activities through February 2010.

### Where can more information be found?

- For more information about birth defects prevention, including a free pamphlet, *"Preventing Birth Defects—Important Information for Michigan Families"* please contact the MDCH Birth Defects Program toll free at (866) 852-1247, e-mail [BDRFollowup@michigan.gov](mailto:BDRFollowup@michigan.gov) or visit [www.migeneticsconnection.org](http://www.migeneticsconnection.org) and click on "Birth Defects & Folic Acid".
- To receive the 2006 Birth Defects Prevention Month packet, please contact Val Ewald by e-mail at [ewaldv@michigan.gov](mailto:ewaldv@michigan.gov).
- For additional information on folic acid or to request a folic acid in-service contact Nelda Mercer, MS, RD ([mercern5@michigan.gov](mailto:mercern5@michigan.gov)), Folic Acid Community Outreach Coordinator.
- For more information on Michigan birth defects data, please visit the MDCH Health Statistics and Reports website at: [www.mdch.state.mi.us/pha/osr/index.asp](http://www.mdch.state.mi.us/pha/osr/index.asp)

*A special thanks for the above information, submitted by Joan Earhardt, Birth Defects Coordinator and Jane Simmermon, Genetics and Birth Defects Follow-up Nurse.*

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